



STATE OF WASHINGTON
WASHINGTON STATE BOARD OF HEALTH
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February 3, 2004

Representative Shay Schual-Berke, Chair
House Financial Institutions and Insurance Committee
342 John L. O'Brien Building
Post Office Box 40600
Olympia, Washington 98504-0600

Dear Representative Schual-Berke,

I am writing as Chair of the Washington State Board of Health and the Genetics Task Force (GTF) to share the GTF's research and recommendations in relation to HB 2772. The Board convened the GTF as required by the legislature in 2002. The broadly based group of twenty-two state and national experts in genetics, civil rights, research, medical ethics, regulatory matters, biotechnology, business, insurance and more transmitted their final report to the legislature last year. The report included specific findings, conclusions and recommendations on several of the topics addressed in HB 2772. I have included a copy of the final report for your information.

After researching the very complex patchwork of state and federal rules and laws governing civil rights, privacy and protection against unfair discrimination based upon genetic information, and after considering this information and public testimony in five day long, public meetings, the majority of GTF members recommended the general policy course pursued in House Bill 2772. However, there were dissenting views on some key points addressed by HB 2772. In addition, the GTF did not identify some of the specific provisions in the bill, and they pointed to some other issues with regard to genetic privacy and discrimination not now addressed in HB 2772.

As currently drafted HB 2772 would define genetic information broadly to include any information about inherited characteristics, including that derived from DNA or other laboratory testing, from family history taking, or from medical examinations. It would require detailed informed consent for any collection, use, storage or disclosure of genetic information outside of health care, with certain exceptions. It would prohibit use of genetic information by an employer or a life insurer to make employment or life insurance coverage related decisions. Finally, it would define discrimination based upon genetic information as an unfair practice within the meaning of the Washington State Law Against Discrimination (Chapter 49.60 RCW), proscribing specific actions by an employer, a labor organization, or an employment agency.

The majority of GTF members recommended a definition of "genetic information" as broad as that used in HB 2772 when used in relation to privacy and unfair discrimination outside the health care setting, particularly in relation to employment and insurance practices (See GTF Recommendation 1.3). HB 2772 appears to apply that definition to all circumstances other than

health care where federal provisions in HIPAA and those in state law governing health care information would govern. This construction seems to reconcile the GTF's recommendations that genetic information be treated as medical information inside the health care setting (See GTF Recommendation 1.1).

The majority of the GTF members recommended that the Washington State Law Against Discrimination (Chapter 49.60 RCW) explicitly include "genetic information" as defined above in the list of characteristics that receive protection under that law. HB 2772 does that in both a general way and specifically by defining discrimination based on genetic information as an unfair practice in employment, in employment agencies or in labor organizations. It also prohibits any request for genetic information of any employee. Finally, it prohibits life insurers from using genetic information to practice fair discrimination between individuals having unequal expectation of life. While I believe these specific provisions of HB 2772 are consistent with the intent of the majority of GTF members, they reflect certain specific judgments neither supported or opposed by our work.

Finally, I want to share with you that the GTF found that protecting our citizens against unwarranted invasions of privacy and unfair discrimination based on genetic information would require clearer information on the considerable protection that now exists in law and more visible locations to which complaints can be brought. The GTF recommended specific actions on this point that appear not to be addressed in HB 2772. (See GTF Recommendation 1.2) There is an overwhelmingly complicated patchwork of state and federal laws, government agency rules and interpretations and complaint investigation and enforcement processes that surround this entire area. Appendix C of the GTF report contains a nine-page Summary Matrix of these laws, rules and administrative arrangements. Researching this patchwork was a major part of our work. Explaining it to the twenty-two experts in this field was a welcome learning for them. The exercise led us all to conclude there is a very great need for patient, provider and general citizen education of the laws now in place.

The Board appreciates the opportunity you provided us to convene the Genetics Task Force. We hope you find its final report and this information useful in your deliberations.

Sincerely,



Linda Lake
Chair, Washington State Board of Health

Enclosure

cc: House Financial Institutions and Insurance Committee Members
Washington State Board of Health Members
Ree Sailors, Governor's Office of Health Policy
Mich'l Needham, Governor's Office of Health Policy
Don Sloma, State Board of Health Executive Director
Steve Meyer, Department of Health